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ABSTRACT

The majority of children with cerebral palsy in developing countries have no access to trained therapists; for example, in Pakistan, there is less than one trained general physiotherapist per million population. In Pakistan, cerebral palsy handling skills were taught to a group of parents, teachers, and paraprofessionals in a series of practical training sessions. A pediatric physiotherapist led the group, in which a total of 37 children, with an average age of 6 years, took part in one or more 3-hour sessions. Assessment of each child was continuous throughout the handling and observation by the therapist. The sessions, designed to meet the needs of the poor and nonliterate mothers, covered developmental patterns, exercises, purposeful positioning for daily living activities, feeding techniques, and appropriate play materials. It was believed that the feeling of group support may have helped sustain and motivate the mothers. Clinic staff enhanced their skills in the group sessions as well, in order to provide more ongoing support for the families. As some mothers traveled long distances to come to the clinic, their attendance was erratic, requiring the group leader to assess as quickly and accurately as possible the degree of disability, the child's mental level, and the family's capacity to absorb and implement a practical plan. (Contains 12 references.) (JDD)

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Handling the Cerebral Palsied Child:
Multi-level skills transfer in Pakistan

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Key words: Cerebral palsy, skills transfer, developing countries, information-based rehabilitation.

Summary: The severe shortage of skills for handling cerebral palsied children in developing countries means that most families receive no appropriate help for home management. In Peshawar, Pakistan, efforts have been made to identify and transfer the basic necessary skills in group work with mothers and allied professionals, so as to make more effective use of specialist time. Some problems and issues are discussed.

Biography: Mr Miles has been administrator in charge of the Mental Health Centre, Peshawar, since 1978, engaging in resource mobilisation for disabled children, publication of rehabilitation literature and policy development with international agencies in the disability field.

Mrs Frizzell (*née* O'Toole) qualified from The London Hospital, Whitechapel, in 1977, worked two years in The London Hospital and then in community paediatrics in Newham, East London. In Pakistan since 1984, she has engaged in part-time private physiotherapy practice and has been advisory consultant to the Mental Health Centre, Peshawar.

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Strategic Framework

THE majority of cerebral palsied children in developing countries have no access to trained therapists. The number of children with disabilities is increasing more rapidly than the pool of available skills. To reverse this trend, strategies are needed that will multiply and distribute information and skills effectively. The concept of 'information-based rehabilitation' has been developed in Pakistan to give such strategies a theoretical framework (Miles, 1987, 1989a). Some of the media such as advice booklets, attitude-change posters and cartoon strip pamphlets, permit rehabilitative information to be multiplied and distributed rapidly, where there is the motivation to do so. Yet their effectiveness is limited in societies where few people can read and fewer seek knowledge from print. Werner (1987), addressing these limitations, emphasises that his massive rural rehabilitation manual is not intended to be a substitute for 'learning through guided practice'.

That is especially true when trying to develop therapeutic skills for the complex problems of cerebral palsy. An array of methods is needed to turn two-dimensional information into three-dimensional practice, at a variety of skill levels. Two-dimensional media such as pamphlets, manuals and radio broadcasts have been used at the Mental Health Centre (MHC), Peshawar, Pakistan. This paper discusses the three-dimensional transfer of cerebral palsy handling skills to a group of parents, teachers and para-professionals, in a series of practical training sessions.

Background Data

Cerebral palsy and polio paralysis account for 71% of the physically impaired children examined at the MHC physiotherapy clinic. Polio paralysis is diagnosed on average four times as often as cerebral palsy. Data from clinics elsewhere in Pakistan's North West Frontier confirm the importance of these two conditions (see table). The Government's immunisation campaign has yet to result in a reduction in polio paralysis (Miles, 1989b). Infant mortality rates exceeding 100 per 1,000 indicate such deficiencies in post-natal care that the incidence of cerebral palsy is unlikely to decline appreciably for some years.

Disabled children assessed at Frontier physiotherapy clinics (1986–88)

Clinic	*Total*	*Polio paralysis*	*Cerebral palsy*	*PP + CP as % of total*
MHC Peshawar	1,572	881	236	71
SAH Mingora	497	243	79	65
RCPD Bara Gate	352	195	56	71
MWCK Kohat	333	282	27	93

The MHC clinic began in 1982 with a policy of encouraging family involvement in rehabilitation. In polio paralysis cases, simple low-cost methods of massage and exercises are taught to the mother or other family members immediately after the initial assessment of the child. Such methods, applied by families at home with periodic check-ups at the clinic, have consistently shown positive results (Rashid, 1986).

Compared with polio paralysis, the range and variety of the needs of cerebral palsied children are very much greater. It is hard to formulate a *universal package* of techniques that can rapidly be taught to mothers for home use. Levitt (1984) draws attention to some of the cultural and environmental factors causing variations in developmental sequence, apart from the effects of supplementary impairments. The Bobaths state that 'No child with cerebral palsy is like another and general advice that might apply to all children is not of much use' – yet this remark appears in their foreword to Finnie's classic (1974) where specific handling advice is given for 'various types of children' with cerebral palsy.

For maximum benefit, a paediatric physiotherapist should spend repeated intensive sessions with each cerebral palsied child and its family, in normal home-like conditions. Resource constraints prevent the attainment of this ideal even in nations with well-developed health systems. The dilemma appears in Andrada's discussion of cerebral palsy in Portugal

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(1986). Andrada emphasises the importance of the mother's role, the Parents' Association, integration, normalisation and decentralised resource allocation. Yet she asserts that inter-disciplinary teams are essential and requires postgraduate specialism for therapists, while seeming to recognise that this desire is unlikely to be fulfilled in the foreseeable future.

In Pakistan, with less than one trained general physiotherapist per million population and practically none specialised in paediatrics, very few families with a cerebral palsied child can receive any specialist advice or demonstration of handling techniques. Even where a trained person may be available, the situation described by Hamblin (1987) in India is typical: 'The overworked physiotherapist spent five to ten minutes running through a few exercises before sending the child home.'

The present study arose through the limited availability of an expatriate paediatric physiotherapist (YF) who had taken part in running a cerebral palsy mothers' group in Newham, London, for several years. Previous experience in Peshawar with expatriates was that either their hands were full with child-rearing or, lacking local languages and institutional framework, it was hard for them to transfer their skills effectively. If they practised at all, it was usually with individual cases in well-to-do families who could use English and could afford to buy special equipment. YF had lived for several years in Peshawar, knew some of the cerebral palsied pupils at the MHC special school, and could make available a regular session away from the needs of her own babies. The special teachers were keen to learn more about cerebral palsy and could bridge the language gap. A new cerebral palsied child was seen at the MHC every four days on average, so a group of mothers could soon be collected. The Pakistani physiotherapist in charge of the MHC clinic was on maternity leave at this time, so it was important to have specialist advice available to the junior staff for reference.

Mothers, Children and Staff

Between February and June 1988, twelve three-hour sessions took place, attended for all or part of the time by an average of six mothers with their cerebral palsied child, two special teachers and, when not too busy with other disabled children, a physiotherapy assistant. A total of 37 cerebral palsied children took part in one or more sessions. The participating parents were self-selected: once it was decided to start the training sessions, parents of all the cerebral palsied children visiting the MHC were invited to take part. The average age of the children was about six years.

The mothers mostly appeared to be poor and non-literate. Normally the custom of *purdah* segregates men and women in public in the North West Frontier, but the occasional presence of fathers in a session did not seem to be a problem to the women present. Cultural norms did mean that it was not appropriate to take photographs at the classes.

Koike (1980), discussing 'mother-child classes' for cerebral palsy in Japan, notes the difficulty for mothers in attending classes regularly if they have other infants to look after. However, the present sessions made a very modest demand on attendance. Most mothers could make some extended-family arrangement to mind their other children, or they brought them to the sessions. Where appropriate, these siblings took some part in handling, positioning and exercises. (The 'child-to-child' method of health education relies on the fact that the care of infants in many countries is often the responsibility of their older siblings.)

Method and Comments

Sessions took place in an exercise room with a large canvas covered foam rubber mat. Activities were conducted entirely on and around the mat, mothers and professionals working with each child in turn and discussing problems and solutions as they arose. Assessment of each child was continuous throughout the handling and observation by the therapist, *not* formal and dissociated from teaching the parent how to help her child achieve goals. It was emphasised that each activity was done with a clear purpose in mind, which was explained to mothers and staff and discussed with them. Each new idea or activity that should be used at home was first demonstrated by the therapist and then tried by the mother. This was repeated until the mother was comfortable and confident enough to continue at home.

The additional aim was that staff participants should learn basic practical assessment and have the means to be selective and realistic in their treatment. Staff necessarily took an active and intelligent part in translating between mothers and physiotherapist. This challenging involvement, during a series of sessions with some familiar and some new families, caused staff to become intimately acquainted with the subject matter and to improve their own communication ability in what had previously been a peripheral area of knowledge.

Many of the cerebral palsied children had been under-stimulated even though they were close to their mothers during the day in their single-room homes. They would mostly spend the whole day lying down, with restricted visual horizon. During the sessions, purposeful positioning for daily living activities was demonstrated, in sitting, standing and prone lying positions, using household equipment or very simple aids. This was one of the main areas reported back by the mothers as being of great benefit in their daily routine.

Exercises were incorporated with positioning in normal developmental patterns, and were explained as such. Most families asked for specific exercises and could understand the need to improve hand control and extension when this was compared with the way their other children had gained motor abilities. Most parents, understandably, began with the goal that their child 'should walk and talk'. One of the purposes of group activity, involving children with similar problems yet whom they could watch with more emotional detachment, was to help parents understand that any progress must start with stages and movements well below their expectations. This idea was reiterated to build up an understanding of what could realistically be targeted for each child.

Appropriate aids of a very basic low-cost type were made by the MHC technicians under supervision or were copied by local craftsmen. Corner seats and standing frames were a success but, where possible, improvisation was employed to avoid delay and to counteract the idea that 'special apparatus' was the key to success. Thus a sturdy box became a corner seat for the child to sit in and a piece of board served as a table for it. Firm foam covered in rexine is commonly available for mattresses, and from this wedges and rolls could be made.

Mothers were asked to bring with them the appropriate household item, for example if feeding was a problem they would bring some food that their child liked, to facilitate demonstration of feeding techniques.

It was noticed that dressing seldom presented as a problem. Most of the families were poor, wearing simple

shalwar-kamiz (pyjama suits), and often the children had no shoes.

Many children who did not communicate needs except by crying were not provided at home with anything to play with. In the sessions, use of hands enjoyably with a variety of play materials was encouraged. An explanation of the importance of hands in gross motor development was stressed to the staff participants, to whom the idea seemed novel. However, staff were fully aware of the importance of play to *mental* development, and were able to explain this in detail to the mothers. Play, positioning, exercises and functional movement were all interrelated during the morning.

Relations in the Group

All parents and children attending the sessions were encouraged to stay for the whole morning unless they had to travel a long distance home. The aim was to achieve a group learning experience as opposed to individual treatment sessions, and to facilitate the learning of handling skills for their own cerebral palsied child by direct teaching and observation of other children.

Mothers new to the group were asked what were their main problems with their child. When possible, on their first attendance, they were asked what were their expectations of the group sessions. This opportunity was given because of YF's previous experience that parents often encounter problems that might not appear to a professional to merit priority, but which cause a lot of distress within the family. To start with these perceived problems is an effective way to win parents' confidence for the rest of the programme.

Group dynamics seem to have assisted in the generalisation of knowledge — mothers soon learnt that what was being demonstrated with another child was relevant to their own. Newcomers tended to thrust their own child forward, but were restrained by others who reassured them that every child would have its turn. The group approach meant that similar points of fact could be reiterated without appearing to insult their intelligence. After seeing the physiotherapist start the assessment of several children, with verbal description of what she was doing, mothers would begin to pick up some idea of what sort of things to watch for. There was no resistance to trying out the exercises, once they understood that this was what was expected.

For many, it was an unusual experience to be expected actively to co-operate with a 'specialist'. The sheer novelty may have motivated some mothers to return regularly for the sessions. As far as possible, no mother was allowed to leave without achieving some grasp of what was going on and what she would be able to do at home. Any parent showing a blank face was gently challenged to say what it was that she did not follow. If she could not communicate her problem, she was asked to copy step by step what the therapist did with the child.

The usual authority symbols of health professionals, such as their white coat, desk, equipment and professional distance, were absent in these training sessions, which aimed for a different sort of credibility. YF sat on the floor, used her own body as equipment, handled the children as a mother would, and was unperturbed by the occasional child who was wet or soiled. The aim was to engage the mothers actively, so that it was possible in a comparatively short time to teach relevant skills, watch them being practised, praise and encourage the good work and correct any faults.

The special teachers and other workers consolidated what they themselves and the mothers had learnt, by working in smaller groups and getting mothers to go over again what they would be doing at home during the week. This was good practice for the MHC staff, and was in any case necessary because of the numbers of mothers involved and the need to use four or five languages during sessions.

Comparing Concept and Attitude

Parents may find it hard to reach an appropriate conceptual grasp of what is cerebral palsy. Initially the notion of *disease* is dominant, with its corollary that parents search for a *cure*. Failing to find a cure, since there is no disease, they may fall back on a fatalistic catch-all concept, thinking that the child has a mysterious, incurable ailment which must be the Will of Allah. Currer (1986) reviews some of the conceptual difference in the ways women from Pakistan's North West Frontier conceive of health and sickness. A feeling of resignation and acceptance is problematical if it removes the family's motivation to help the child develop and learn.

Given the tendency to conceal severely disabled children, the *purdah* restrictions on women's mobility, and that the incidence of moderate to severe cerebral palsy is probably less than 1 per 1,000, the mother of one cerebral palsied child may well never have seen another such child. Seeing a group of cerebral palsied children at close quarters, watching and taking part in their movement and activities, may prepare the parent for a significant shift both in knowledge and concept. The knowledge required was practical rather than theoretical: there was no need for parents to attempt to grasp the basis of neurological lesions in the immature brain. The Newham group of mothers in fact had access to far more theoretical information than the Peshawar mothers, perhaps even more than they were able to assimilate.

Pakistani women normally face life with the support of their close female relatives. But when a severely impaired child arrives, sisterly support may be flawed by negative attitudes. To become part of a group of mothers sharing a similar experience could be a useful substitute for what would normally come from the extended family. Some such relationship appeared to take place among the mothers.

The feeling of group support may have helped sustain and motivate the mothers subsequently, but they were unlikely to benefit from any other support, in contrast to the Newham mothers. The latter knew that an extensive official framework of support existed, and they were more assertive in demanding their children's rights.

In general, however, the similarities between the Newham mothers and their Pakistani counterparts were striking, considering the substantially different cultural contexts. The Pakistani mothers participated more actively and vocally than had been expected, asking questions to clarify advice, inquiring about the efficacy of 'medicine' to help their child, taking some interest in children other than their own. The hopes and fears expressed by some of the Pakistani mothers about their children's future were verbally identical with those spoken by Newham mothers.

Problems and Attempted Solutions

The number of attenders grew during the first few weeks, including some from towns and villages up to 50 miles distant whose attendance was erratic and who might arrive at any time during the session. The initial plan was for an orderly, incremental exposition of practical handling of cerebral palsy, whereby mothers could learn, practise at

home and return to learn further. A conflict of priorities arose between this plan and the need to ensure that mothers from distant places should go home with enough practical and credible experience to carry them further even if, as appeared likely, they might not attend again for a long time.

The group leader needed to be able to assess as quickly and accurately as possible the degree of disability, the child's mental level and the family's capacity to absorb and implement a practical plan; and then to devise such a plan and explain as much of it as seemed appropriate. However, it appeared that neither teachers nor mothers understood the relevance of normal developmental milestones of gross motor activity, which would normally be cited in explaining a handling and treatment programme. (For the Newham mothers, developmental milestones had been part of their 'general knowledge'.)

The teachers confirmed that the cerebral palsied child, in the normal home environment of a poor frontier family, is at considerable disadvantage compared with the able-bodied child in terms of available stimulation. The normal child finds his own play-things, or makes them for himself, eg stick and hoop, water play with mud dams, kite flying, pitching stones. Few toys are available or affordable. There is very little children's radio or television. So the cerebral palsied child is liable to gross under-stimulation, the family being unaware of the need to involve the child in as many activities as possible. Advice therefore focused initially on sitting postures that should facilitate both feeding and visual stimulation.

With families who might attend only one session, demonstration of basic positioning to facilitate development along the most functional lines was a priority. However, the conflict of priorities was keenly felt – how much time to devote to teaching very basic principles to a family who might never again receive any specialist advice, and how much to concentrate on moving forward with families who had made the effort to return several times. In due course, a specific package was devised of large-scale diagrams and appropriate basic techniques for use with single-session attenders. This package was presented and worked through on an individual basis, to consolidate what they had picked up in the group session.

Watson (1986) notes that the physiotherapist in a developing country needs to 'look at her role in management terms rather than attending just to the physiotherapy tasks close at hand'. Such a review could result in the sort of multi-level skill transfer studied here, to increase access to skilled persons. But even such a policy cannot disguise the fact that the majority of families needing help are likely to get very little.

In Conclusion

In a normal referral system, a similar amount of contact time with a cerebral palsy specialist, averaging three hours a week over three months, might have provided therapy for three cerebral palsied children. At a college, the time could have provided a series of lectures to trainee health personnel. In the situation described, no systematic quantification of benefit was practicable. However, the multi-level approach described here appears to have:

- Made a much broader use of the same specialist contact time.
- Directly benefited ten times as many cerebral palsied children.
- Provided their mothers with greater stimulation and motivation to engage in home treatment.
- Given practical skills training and demonstration to both special education and physiotherapy staff members.
- Enhanced inter-disciplinary collaboration and respect.
- Reinforced the policy of parent/professional *joint responsibility* for rehabilitation.

In trying to increase the number of beneficiaries there is always some danger of diluting the quality of care and attention to individual needs. However, in one-to-one interface between specialised therapist and individual care-giver, when the latter is uneducated and unaccustomed to concentrated learning of skills, there is a limit on what the individual can absorb at one time. The group experience, with repetition, cross-questioning, recapitulation, provides far more variety of learning opportunities and more time and encouragement for the formulation of questions.

This approach was highly demanding of the specialist, but also rewarding in terms of multiplied effectiveness. The next stage envisaged is to run a further series of clinics under cameras, to produce one or two carefully edited videos with commentary added, showing the handling skills and the learning processes at several levels, in the visual context of Pakistan. This should be a further effective means of making one specialist's experience stretch to far more people than she could ever treat or train individually. Preparation of a culturally appropriate, multi-media 'learning package' would also lead to a more formal definition of skill transfer targets and a controlled evaluation of success.

An incidental observation from the study was the striking similarity in the reactions and participation of the Peshawar mothers compared with a group of mothers in Newham, London. The experience of having a child with moderate to severe cerebral palsy seemed to override what would otherwise be very considerable socio-cultural and educational differences.

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